

**Alzheimer's Disease State Plan Task Force
Community Forum – Columbia, MO
Wednesday, January 27, 2010
5 – 7 PM**

Introduction from Executive Director of the Mid-Missouri Chapter of the Alzheimer's Association Linda Newkirk

Introduction from Jerry Dowell, Deputy Lieutenant Governor of Missouri and Chair of the Alzheimer's Disease State Plan Task Force

Presentation by Carroll Rodriguez, Missouri Coalition of Alzheimer's Association Chapters

Dr. David Oliver, Assistant Director of the MU Center on Interdisciplinary Aging – Facilitator

40 – 45 people (not including taskforce); 15 taskforce members

Questions/Discussion

Dr. David Oliver's Introduction

His own story of being a caregiver of his great aunt in the late 60s/early 70s. Identified us all as connected by Alzheimer's disease (AD).

Caregiver – Columbia, MO

Her husband has dementia. He started in an assisted living facility and is now in a skilled nursing facility – private pay – in Lenoir (Columbia, MO). There are not many skilled nursing facilities in Columbia; they are not readily available. The only way they can be in a skilled nursing facility is through private pay, which they are lucky to afford. A nursing home is NOT his home and it never can be. We need to revamp nursing homes – brighter, more staff to individuals, more homelike and like a family. Two patients in a room is not like their home; it is not good for patients or easy for the family members that visit.

David Oliver (Facilitator) – Columbia

Some homes will deny patients because of behavioral issues.

Caregiver – Clark, MO

His wife's symptoms began in her late 40's. Both are RNs. The diagnosis was slow; they traveled the state to various types of doctors: one thought it was a brain tumor, one said depression, one said adult attention deficit, one gave her medication that helped her loose weight – not good. One gave her medication and said take it for 3 weeks and she should be better -- that depressed her, and she stayed in bed and was a zombie for 3 days – the only good thing was that it freed him up from her questions for 3 days, but he took her off that medicine. It took several years to find a physician that finally did a mini-mental exam. After several years of searching, the diagnosis came in 15 minutes. You can't start living until you have a diagnosis and you know the problem you are facing.

Medical institutions need to be more up to date on persons with Alzheimer's at a young age. No physicians suspected Alzheimer's due to her age and weren't willing to consider the possibility.

Caregiver – Columbia, MO

Wife had AD and died a few years ago in a nursing home. Two issues 1) Could have kept his wife home longer with home care and some money assistance but felt he had to place her in a nursing home prematurely. 2) Reduce restrictions on stem cell research to improve the prognosis for Alzheimer's. Research needs to move forward.

Caregiver – Columbia, MO

Husband was misdiagnosed with numerous illnesses in 2003 then finally correctly diagnosed with AD in 2004. He died 2 years ago. While alive, he made numerous trips to the hospital where the staff had a difficult time dealing with Alzheimer's. The hospital environment was detrimental and he lost ground with each visit. We need better training for hospital staff; had his hospital visits not been so difficult, he would have lived longer. The upside is that his condition worsened to the point that they were able to use Hospice longer than others and that was incredibly helpful. Hospice needs to be a more readily-available option for people. They were lucky to have a good insurance policy, but she thinks of the people who don't have that.

Caregiver – Columbia, MO

Her husband had Parkinson's but luckily in MO he could go to a State Veterans home. Missouri State Veterans homes give good care and training to family, which was helpful to have. Contact her daughter Nancy in staff development at the Veteran's Home in St. James, MO regarding training courses for family members of those with dementia. These Missouri State Veterans Homes are wonderful!

Caregiver – Columbia

Her husband is currently in the Mexico Missouri State Veterans home, which is providing excellent care. She tried three in-home health providers but he rejected them; weren't working out. We need improved training of in-home health workers to keep loved ones at home. All nursing homes should be regulated by the state so that the care can be comparable to that of the Missouri Veterans Homes. They need to have that training they give there for everywhere. She travels to see him – not every day – but often. Her mother is currently in another nursing home and receives, in comparison, very poor care. She wishes her mother could have comparable care.

Caregiver – Columbia, MO

We need to focus on the future of what can be done. Hopes that more caregivers could be on the taskforce to encourage the state to bring in more money for caregiving. We need funding to treat Alzheimer's. Patients need better facilities. Long waiting lists for facilities and services, such as special care units. It is not the person with Alzheimer's who suffers from this disease, but the caregivers. We need more money to support caregivers. Additional money is required for the building of these Alzheimer's facilities. Hope we will reach the point where there's no need for skilled nursing facilities because Alzheimer's is cured.

Caregiver – (No town given)

Here tonight with one of his sisters, and they represent two of the four caregivers for their father. They are fortunate that their mother is healthy and can take care of their father at home. They are also fortunate that sister works for the state and has excellent benefits and family leave with pay that she can use for the care of father. He and his sister do not have the flexibility to leave work. Need to encourage this workplace flexibility for caregiver's leave. Todd has moved in with parents to help support his father's care. Lucky that he is a WWII veteran – nurses come twice a month and medications are paid for. Lucky that Alzheimer's Association provides respite dollars, but that money is now less than last year because the state cut funding. Mom can only take off 5 hours a month when she really needs 5 hours a week. Namenda (drug) is now not covered so she has to pay for Medicare Part D just for that one drug. Since mom can't drive, it takes two people to help with her respite – one to drive mom and one to stay with dad. The list is pretty simple, and it comes down to money: 1.) money for research, 2.) money for prescription assistance, 3.) money for physical items and equipment to help AD patients (special grips in the bathroom, wheelchair accessibility, etc), 4.) money for GPS to help with wandering, 5.) money for respite care and caregivers.

Person with Dementia – Columbia

Has AD and lives in the basement apartment of her daughter's home with the grandkids. She considers herself very lucky. She stays busy (currently working on a quilt), and she tries to focus on the positive. Glad to have her daughter. It's a happy life but also depressing to know of deterioration. She hopes we can find a cure for Alzheimer's before anyone else in the room has to face this disease.

Daughter of the Above Person with Dementia - Columbia

I was 18 years old when Mom and I began helping my grandmother who had Alzheimer's. I was 34 when my mother moved in with us. My daughter is now 11 years old watching her grandmother go through this disease. I wonder what age my own daughter will be in *I am ever* afflicted with Alzheimer's. The number of Alzheimer's patients continues to grow. We need more research money, and we need to cure this disease soon before it plagues my entire family.

Caregiver – Columbia

In June 2008, his wife was diagnosed with Alzheimer's, and they live here in Lenoir. Things got bad in April 2009 – she started packing her bags in the middle of the night and wanted to be taken to her new home. So they packed things in boxes, put them on a cart, walked up and down the halls while she was reading the names on the doors. Once she found their name, they moved back into the same room. On April 26, 2009, he had had enough. His daughter came in the middle of the night to take her mom for a ride, and when she came back, she couldn't remember that her room was her room.

Now at her new home, she believes that she has to take people to the jail. He doesn't know where this occupation came from since she has nothing similar in her past that he is aware of.

Lenoir takes them for country rides. One day when they returned she insisted after lunch that they needed to get back on that bus. He could not figure out why she wanted to leave but eventually realized she thought they were on a tour so needed to get on the bus to go home. He

had a terrible time re-directing her. One day when she was the worst, the Director of Lenoir told him to leave her – it was hard to do this, but he knew it was the correct thing to do in this situation and it worked.

Today, she thought her brother (who's in Florida) was in an accident. They have a son in Connecticut and a daughter in Arizona. She cannot understand why they don't visit. Distance and time mean nothing to her. Always something new – has to find ways to deal with it. You just learn to go along with the person's story each day.

Caregiver – (No town given)

Just beginning journey – her husband was diagnosed with AD 3 years ago. Two-and-a-half years ago, she went to an Alzheimer's Association event "You Gotta Laugh" with David Oliver, and her world was opened up to her. She finally realized she wasn't alone and that there are resources out there. She is blessed with these resources. Whatever the Association needs – should be given that support. Janie's program (Project LEARN – early stage outreach) has been wonderful. She also used the Alzheimer's Association for home safety modification ideas, and when an occupational therapist came by to their house recently, she was surprised by all the safety measures they already had in place.

Caregiver – Rocky Mount, MO

His wife has had Alzheimer's since April 2009. We must advertise what is available in the state to Care Givers. People need to get services early – do not wait until last minute to get help. Some people have heart attacks before they are informed of the help available to caregivers.

Caregiver – Columbia, MO

Mother and husband have AD. Two considerations: Cost and Education.

COST – Start helping families keep persons at home. Paying for in-home care is more cost-effective than placing people in nursing homes and then asking the state to pay for institutional care. Investment now at a lower level is better than higher level later. We have to plan for the future.

EDUCATION – There is ShareCare money (MO tax credit for caregivers) of \$500 a year, but not many people know about it. That money is a psychological boost for caregivers that they are valued.

Rural communities have fewer resources. Her doctor doesn't believe there is Alzheimer's and that the medicine doesn't work, but he gives them the drugs anyway because she insists. Need to educate medical community. Need to make Missourians aware of the services available to them. Hospice services are a blessing and must be readily available to caregivers.

Caregiver – Moberly

She is an in-home health provider/nurse and was a caregiver at early age for grandmother. Grandma moved in with her family, and the diagnosis was slow. Now, her mom has Alzheimer's. The issues addressed tonight have all been good. Dad has had to take over the role

of caregiver, and she has just switched to a new job where they are not as supportive of her taking time to care.

In home services needs more funding. Her son works for an in-home service and is responsible for driving to rural areas to care for patients, but with high gas prices and his low pay (\$7.50 per hour), he barely makes any money. Those in in-home services barely make any money, and the families can't afford to pay more. They need more money to keep quality staff in these positions.

More funding for research, medications and Rx plans, and support for in-home care. Medicare part D: medications cost \$140 month – people will choose to pay living expenses rather than pay for expensive medications. She's particularly concerned about "the donut hole," – a period where the enrollee is responsible for paying full-price for medications. Enrollees receive reduced-rate medications up to a certain dollar amount and then they begin "the donut hole," where medications are full-price. After they reach a certain cap, medications after that are free or greatly reduced.

She loves the Alzheimer's Association.

Caregiver – Columbia, MO

Cost of drugs, such as Aricept and Namenda, in the doughnut hole can reach \$500 per month.

Caregiver – Columbia, MO

Doctors need paperwork renewed every few years – young doctors are more informed on Alzheimer's. New doctors should be taught about AD. If you as a caregiver don't think that your primary care doctor understands AD or is not providing appropriate care, get out. She lost her health insurance last month. She can't return to work due to her poor health after being the caregiver for her husband.

People need to be educated to ask better questions – she's worked in social services and still didn't know what to ask. Alzheimer's Association is wonderful! She's in a support group for both caregivers and person with dementia. Caregivers are taught to take care of themselves first. People in rural communities, though, are unable to get anyone to come into their homes to assist the caregivers.

Dr. Oliver (Facilitator) – Columbia

Look at medical effects on caregivers. Illnesses they have from stress.

Caregiver – Columbia

Mother had AD and father kept her at home until mid to late stages. On required trainings, who monitors that training? On occasion that her mother had to go to facilities – it was bad. Facilities need attention and improvement.

Caregiver – Jefferson City, MO

She has been a private care giver for 8 years – private paid. She cared for a man for five years before he was asked to move to a different nursing facility because he couldn't walk. Family

lives out of state, so they placed him in a private place. She hated that he was *forced* to go and felt it affected him badly.

Both families and facilities need to be EDUCATED. Training needs to be better. When her friend went to the hospital, it was a disaster; nurses in hospitals need training. There is normally a waiting list for facilities. Caregivers need help with training while on the waiting list so that the loved ones waiting to get into the facilities receive good care at home.

Caregiver – Clark, MO

He is also a teacher at the Career Center – Columbia High School. He teaches 17-18 year olds to become CNAs. He takes them to facilities so they will not be overwhelmed as professionals. They are better at handling situations with people with dementia because they have no responsibility in life at this age. CNAs in the field are often underpaid and overworked so have no motivation to try hard to care well for people. You get what you pay for.

He has his RN and Masters in Education, but he is in fear of his job being eliminated due to budget cuts. If he were to find a new job, he may not be able to get insurance because of pre-existing health issues of both he and his wife.

For 20 years, they have been talking about Alzheimer's cures – nothing has happened. In the 50s and 60s, a diagnosis of cancer meant you were doomed. In the 80s and 90s, HIV/AIDS meant you were doomed. Now, you can LIVE with those diseases; they are treatable. That's not the case with Alzheimer's. We need to force them to do more research and give more support so that, some day, Alzheimer's treatments will be a reality.

Caregiver – Moberly, MO

Remember the rural areas – they need help. There should be a registry of providers and services. There's also a need for more adult day centers. Parents missed the Medicaid cutoff by just a little but get Title XX funding. She hears rumors that legislators are going to let Title XX go, but we need that funding.

Caregiver – (No town given)

A more comprehensive guide to resources is needed.

[Response from audience]: Alzheimer's Association has many services and resources.

Caregiver – (No town given)

[Wife left note (mother had AD):] When her mother was in nursing home, there was never enough help per patient. Not enough training/education for nurses or aids; not enough staff in nursing homes; 1/10 ratio of staff to patients in Special Care Units. Know it's funding – but there needs to be more staff. To the taskforce, not sure where money will come from, but just keep an open mind going forward in listening to the other forums. Let the governor worry about the money. We need to focus on the possibilities.

Caregiver – (No town given)

Caregiver for mother who was finally diagnosed in 2000. Daughter knew something wrong since 1993 and, as a librarian, had done her own research. Explained issues to her doctor to try to

convince him to finally diagnose her mother properly but he wouldn't listen to her. Mom was refilling medications weekly from the pharmacy. Daughter asked the doctor to call the pharmacy to stop this from happening, but he wouldn't due to HIPAA restrictions.

When mom fell in 2004 and went to hospital, doctors and nurses kept asking mother what was wrong and never asked daughter. She tried to tell the emergency room staff that her mom had dementia so would not be able to explain what happened; every person that talked to her mom heard a different story.

Mom was always strong-willed and frugal, which is helping to pay for her care. Mother had foresight to set up a POA, trust, will, etc, but she is still determined to be competent. If PWD is compliant, it's fine, but if they are not, caregiver is the bad guy. Legally, she was still competent, though in reality she couldn't make even the most basic decisions for herself. Mother reported her kids to the police that she was being held against her will in assisted living. Daughter had to go to court to obtain guardianship, but doctor was still not helpful and would not sign papers. They had to go to a specialist to get papers signed. After getting guardianship and durable POA, side-effects of anti-psychotic drugs caused illness and doctor wouldn't take her off for 6-months. She had to do her own research to find out side-effects of drugs.

Mother's care costs \$70,000/ year. Even though mother was frugal and had saved so much, she's still worried about what will happen when money runs out. Her mother's body is likely to outlive her brain. Worried about her children having to face the same with her.

Caregiver and family members need training. Need more training of staff in facilities.

Caregiver – Boone County

Boone County has a Boone County Resource Directory of Senior Services (distributed by Senior Network); it is an excellent recourse. Have that statewide would be wonderful with resources for all communities.

Caregiver – (No town given)

Response to caregivers:

- Alzheimer's Association has a GPS system called Alzheimer's Association ComfortZone, powered by Omnilink.
- Boone County Resource Directory of Senior Services (distributed by Senior Network) is available online

Gwen Richards – Taskforce Member – Kansas City, MO

Acknowledged that comments are heard and felt by taskforce board. Mother and brother passed away with AD and her two older sisters have AD now. She too has Alzheimer's. She had to leave her job after 25 years – she knew something was wrong with her. The taskforce gives her a purpose – she represents the people here and their stories.

Linda Newkirk – Alzheimer's Association Mid-Missouri Chapter Executive Director

Many of those serving on the Task Force are or have been caregivers.

Caregiver – (No town given)

Mother has undiagnosed AD, and the Mini Mental Exam showed she was moderate. Her mother's monthly bill at her living community just went up to \$700 but she is not going to move her from the community is comfortable in.

She is facing a "Double Whammy" because her older sister is mentally retarded, and her mother can no longer be the guardian of sister. The courts have said that the mother needs to be there in court, but the mother, in her mind, still thinks she needs to be and can be the caregiver and won't give that up. What can I do?

[Response from audience]: See an elder law attorney for help.

Lois Zerrer – Taskforce Member and Elderlaw Attorney – Springfield

Don't be afraid to speak to an attorney. It gives you peace of mind. Let someone help you because every situation or circumstance is different.

Caregiver – (No town given)

He used an elder law attorney to be put on as a guardian for mother. Go to attorney, may be expensive – tell them help you do what YOU want to do

Read From a Card

We need affordable care for my husband. It seems that what it costs to provide care is just worth quitting work. But must work so that they can have that insurance.

David Oliver (Facilitator) – Columbia

Do not let THIS forum be the last time we are heard. Continue to send comments, concerns, suggestions.

Caregiver – Columbia

Who or how was the Task Force selected? (Explanation followed)

The taskforce was created by legislation in 2009 and will continue through November 2012. Community Forums such as this one will be held throughout the state.

Closing**Submitted Written Testimony #1: Caregiver – Florence, MO**

1. This is a long journey and very challenging
2. Physicians need to be able to diagnose Alzheimer's disease better.
3. Help for those families trying to keep their loved ones at home.

Submitted Written Testimony #2: Caregiver – Jefferson City, MO

My husband, Richard, has Lewy Body Dementia. At age 61, he was diagnosed by a neurologist at Washington University in St. Louis. Concurrently we were providing assistance and over site to my mother, who had some kind of dementia, (she lived 2 hours from us), and so for many

months I did not realize the impact of what was happening to Richard and believed, at the time, it was due to the stress of dealing with mother's issues.

This has been an experience that I wish on no one but many are to follow from the statistics I hear about on the news. The news media focus is on research, which of course is important, but those dealing with the disease day-to-day need help NOW.

More respite care is needed at affordable prices for people that do not currently meet the qualifications for financial assistance. Family Care partners/caregivers are so stressed and exhausted, that statistics support this disease takes more than just the individual with the disease.

Home health care services that are affordable for more people would keep people out of skilled nursing facilities for a longer period of time. Perhaps some changes in this area would benefit many in need.

For those without long-term care insurance, or without other avenues of financial help, most likely will see the family assets exhausted when nursing home care becomes necessary. My husband and I have been frugal with our money and always believed that we were responsible for our financial future. Prior to my husband's diagnosis of dementia, we applied for long-term care insurance, with another company, but of course he does not.

Doctors need more education in the area of dementia. I have a friend who was told by her physician that she had Alzheimer's. She went to Washington University for a diagnosis and found it was her medicine causing the memory loss, not dementia. I do not believe this is an isolated case.

I live in the Jefferson City area and would be available to talk with any member of the Task Force. Unfortunately, I am unable to attend tonight because of my limitations of driving in the dark.

Submitted Phone Testimony #1: Caregiver – (No town given)

She receives respite reimbursement from Medicare to pay for someone to bath her husband and give her some time off. But the only way he can qualify for this funding is if he's "homebound." This means he can only leave the house for a doctor's visit or church related activity. When he was on hospice (he was taken off once his condition improved), this restriction was not attached to the funding. So, on days when he felt good, they could go out to dinner or for a ride. Now that he's off hospice and only qualifying for Medicare respite, she's feeling trapped. She feels the Medicare restriction of "homebound" is punishment to her instead of helping him. She can't stop respite reimbursement from Medicare because she desperately needs someone else to bath him (he's too combative and disagreeable if she tries to do it). She feels her only other option is to place him in a nursing home in a Medicaid bed, which is something she's starting to seriously consider.

Submit additional testimony to Carroll Rodriguez at carroll.rodriguez@alzstl.org.